

Palliative Care and Quality of Life Interdisciplinary Advisory Council

February 28, 2014 Meeting Minutes

Members Present:

Jean Anderson, R.N., CEO, Visiting Nurses Service of Newport and Bristol Counties; **Maria Barros, R.N.**, Director of Clinical Services, Nursing Placement, Inc.; **Rev. Marie Carpenter**, Director of Eldercare Ministries, American Baptist Churches of Rhode Island; **Dr. Linda DelVecchio-Gilbert**, Associate Professor, New England Institute of Technology, Nursing Department; **Linda M. Dziobek, R.N.**, Chair, Partnership to reduce Cancer in Rhode Island; **Chair of the Advisory Council, Dr. Edward V. Martin, M.D., MPH**, Medical Director, Home and Hospice Care of Rhode Island; **Dr. Angela Taber, M.D.**, Palliative Medicine Physician, Miriam Hospital and Rhode Island Hospital; **Dr. Joan M. Teno**, Professor of Health Systems, Policy and Practice, Brown University School of Public Health.

Members Not Present/ Excused:

Nancy Roberts, MSN, R.N., President and CEO, VNA of Care New England Health System (excused)

Staffing the Advisory Council:

C. Kelly Smith, MSW, Comprehensive Cancer Control Program, Rhode Island Department of Health

Members of the Public Present:

Todd W. Ellison, MSW, LICSW, American Cancer Society Cancer Action Network; **Gloria Hincapie, HE, MR**, Leukemia & Lymphoma Society; **Bill Koconis**, Leukemia & Lymphoma Society; **Arthur Plitt**, Women & Infants Hospital of Rhode Island; **Susan Roberts**, American Cancer Society Cancer Action Network; **Tina Spears**, Rhode Island Parent Information Network

Present from Rhode Island Department of Health (HEALTH):

Dr. Michael Fine, M.D., Director, Rhode Island Department of Health; **Twila McInnis**, Director of Nursing, Rhode Island Department of Health

Minutes:

1. Introductions, Roll Call and Establishment of a Quorum (Chair)

Dr. Martin welcomed and thanked the Council Members and Members of the Public. He then called roll (results above). A quorum of the Council was determined to be present.

2. Welcome from the Director of HEALTH

Dr. Fine welcomed and thanked the members of the Advisory Council for their service. He explained that HEALTH embraces the work of the Council, and will look to its members for advice regarding how best to move HEALTH efficiently toward its Palliative Care implementation goals. The Council will advise the Director of its professional opinions and suggestions via memo or letter, and HEALTH will respond.

3. MOLST (Medical Orders for Life-Sustaining Treatment)

The Council then discussed MOLST (Medical Orders for Life-Sustaining Treatment), as called for on the agenda.

Dr. Martin, Dr. Taber and others observed that the required dark pink paper for the MOLST form doesn't scan or fax well (if at all) because the required paper color is too dark. Specifically, the paper turns to an illegible dark grey when photocopied or scanned. Dr. Martin and Dr. Taber noted that MOLST is not being issued on pink paper at two area hospitals. Dr. Martin observed that the paper document is really needed in an electronic format. Drs. Martin and Taber agreed that it should be coded to be scanned in and retrievable under the code status.

Dr. Fine stated that the form is being converted into an e-document for CurrentCare. Providers can help by making sure that there are enough enrollees to implement its use. Ms. Barros and Ms. Anderson noted that their organizations are working with others to enroll patients, and that they are promoting enrollment through their clinic managers, who are also well-connected with cultural communities.

Dr. Fine urged the Advisory Council to put their recommendations and concerns about MOLST and any other issues, suggestions, or concerns they may have in writing and to submit them to him. HEALTH will then respond as appropriate. Dr. Fine then excused himself, as he had another obligation.

Dr. Teno suggested that HEALTH target its resources for those who need MOLST the most—nursing homes, and especially hospice populations in those facilities. She suggested that perhaps a branded logo or border rather than the pink paper could be used to distinguish MOLST from other standardized forms. This would prevent the barriers to scanning resultant of the pink paper.

All agreed that because MOLST is a medical order, it should follow the patient wherever s/he goes. Dr. Teno asked whether patients could wear a special bracelet indicating that they have a MOLST, to inspire providers to look for it. When a patient arrives at a hospital without a current MOLST, the hospital may need to create another, which is not always possible for a seriously ill person. Ms. Barros asked, might we add a MOLST sticker to a ComfortOne bracelet? Providers among the council members were unsure whether another bracelet would be effective, but perhaps a medical alert with a link to a website/ the patient's most recent MOLST would be good.

If one method of identifying a patient with a MOLST won't work, perhaps people should be given a variety of possible interventions. Other ideas included a refrigerator magnet, a barcode that could be scanned and linked with the most recent MOLST, more patient education, introduction of overnight education video programs via cable TV, and an educational YouTube fireside chat featuring Dr. Fine.

After further discussion, the advisory council made several multifactorial intervention recommendations regarding MOLST.

- a) Add language indicating that the patient has a MOLST to the Continuity of Care form.
- b) Add patient information regarding MOLST to HEALTH's website, including, perhaps, a YouTube fireside chat with Dr. Fine.
- c) Create a webpage with MOLST resources for providers, including instructional video content for PCPs.
- d) Make sure that MOLST is incorporated into CurrentCare.
- e) Adopt a universal method of determining that a patient has a MOLST in place, and train providers and first responders accordingly.
- f) Make MOLST available to patients and caregivers in languages other than English.
- g) Set up a Palliative Care Grand Rounds.

4. Topics for Future Consideration at Meetings:

The Advisory Council recommended that at the next meeting, the group should define what palliative care and advanced palliative care management are, in order to guide practitioners and the general public. Specifically, the group should determine:

- How to distinguish palliative care from end-of-life care
- How to describe symptom management affecting quality of life to patients
- How the forthcoming IOM report on palliative care should help to shape Rhode Island's practices; Dr. Teno is on this IOM committee and Brown University has run about 10 years of data that might suggest good state specific protocols or interventions. The advisory council agreed to look at these next month.
- How better to time palliative care referrals; home care and nursing homes have little time to work with families of hospice patients because they do not start the process of palliative care soon enough.

More resources are needed to provide palliative care to people in Rhode Island, particularly outpatient options available through primary care providers.

Members of the public suggested the following topics for further consideration:

- Look at Rhode Island's general laws for a legal definition of palliative care, and use that as a starting point next time
- Consider pediatric palliative care issues (as they are many times different from those of adults)

5. Future Meetings

The Advisory Council members unanimously agreed that they will meet every other month, on the last Friday of the month, from 3:30pm to 4:30pm. Next meeting dates are as follows:

- April 25
- June 27
- August 22
- October 24
- December meeting is TBD

6. Adjournment

The meeting was adjourned at 4:35pm.

(Minutes reported by C. Kelly Smith, MSW)